

## CFS PHOENIX

<b>PHOENIX RISING: A CFS/FMS NEWSLETTER</b> by Cort Johnson	<b>SPECIAL EDITION: The Advocacy/Support Group Interviews I</b>
<u><a href="#">Subscribe to PHOENIX RISING!</a></u>	A Talk with Pat Fero of the Wisconsin Chronic Fatigue Syndrome Association

The CFS/FM support groups perform a lot of vital functions for CFS/FM patients; they provide advice, physician and legal referrals, emotional support and they advocate for change usually on a bare bones budget. Often run by people who themselves have CFS/FM they are the bread and butter of the CFS/FM community...and there is some fear they are fading. Dr. Bell has referred to the diminishing activity of CFS/FM support groups over time - something he thinks has dangerous implications for the CFS/FM movement as a whole.

*"In recent years there has been, in my opinion, an apathy that has crept in and pervaded some parts of the support community. Perhaps it has been due to ill health, perhaps the patient community is giving up, discouraged by a perceived lack of progress. Maybe it is that the old-timers are just getting older. But whatever the reason, people need to remember that nearly everything good that has come to patients with [M.E.] CFS has come via the support community. So, support people, don't give up. Don't get discouraged. Follow your hopes/dreams/passions, and if this includes activism, get involved."*

In this series we ask the leaders of these organizations to tell us about these bedrocks of the CFS community; how they were formed, what issues they are engaged in, what opportunities and pitfalls they are facing, how they are doing and what they believe are the critical issues facing the CFS community.

### A TALK WITH PAT FERRO

#### OF THE WISCONSIN CHRONIC FATIGUE SYNDROME ASSOCIATION

We begin this series with an extensive interview with Pat Fero, the leader of one of the oldest, if not the oldest operating CFS Support/Advocacy groups in the U.S.; the Wisconsin Chronic Fatigue Syndrome Association (WCFSA) (<http://www.wicfs-me.org/>).

A longtime CFS patient Pat has engaged in support/advocacy work on either the local or national level for over 20 years. She was presented the PANDORA Female CFS Advocate of the Year at the 2007 IACFS Convention.

*(I) Pat, can you briefly tell us your story with CFS; when you got sick, what happened and what changed for you then?*

My husband and I went to England for 10 days in late June of 1980 with a group of friends. I don't remember getting sick there, but Bruce said I was. What I do remember was having the headache from hell that seemed to go all the way down my neck into my back. By the time I got around to taking a temp when that pain went away and I thought I felt better, I had a fever of 104.

When the school year resumed, I recall only bouts of feeling dizzy then very tired for short periods of time. Within a year little symptoms came up, like tingling in feet and hands and a

continual echo - ocean sound in my ears. I became pregnant with my son and was ill the entire 7 1/2 months when he was born via c-section.

Gradually, the incidents of dizziness increased and with them, longer times of exhaustion. I know my blood pressures were low as well as my body temperature because of the C section in 1982 and hospitalization for another surgery in 1982. I did not know until later that I did not recover well from the surgical drugs

I worked until October 28, 1988. By that time, I was exhausted, could hardly climb the stairs to my classroom each day and my brain was shot. I had viral symptoms all the time including cold sores from just under my nose to my chin. I was a wreck. It never occurred to me until that Fall that I HAD to quit work. My 2 kids and my husband got leftover mom and believe me there was not much to go around. I often said that I felt like a doorknob. Just there...no sense of self....just there.



*(2) The WICFS website states the group was begun in Ruby Nakamura's living room. Can you tell us about this; how and why the group got together, how many people were there, how you knew each other, etc.?*

In the fall of 1986, Newsweek printed an article on CEBV or chronic mono. A teacher brought the magazine to me in my classroom. I called Portland to find that an entire population was experiencing the same crap symptoms as I had had for years. The Portland group gave me Ruby's Milwaukee number. Ruby took names and when she had 20 or so, she called us to set up a meeting in the winter of 1986. By 1986, it was a daily fight to stay upright, but I was still teaching. I clearly remember that people had symptoms from head to toes and it felt good to be able to talk about all the odd sensations and the severe problems with thinking.

**(3) In physical terms what did the WCFSA look like? Did you have a phone line, an office?**

Until 1999, WCFSA business was conducted from home. Ruby, Genie Gengler and Jack Hale from Milwaukee did most of the work. By 1992, we had good size telephone trees in Madison and Milwaukee, had seminars twice a year and began to set up a state support group network. I was an officer by then and answering patient phone calls.

In 1992, when Ruby died of a stroke, I presided over my first meeting. I was frightened. Could I follow Robert's rules? Could I even follow a pushcart of thought?

We began to get more board members from Madison. I moved to Sun Prairie once I quit work in 1988, so the Association business was in my home until office space was donated in 1999.

**(4) What does the physical environment of the WCFSA look like now?**

We have a 3 room office suite with one telephone. The computers and fax machines are at the homes of our board members. Our office manager goes to the office once a week to get messages and open mail. We have a library, many archived medical articles, a good copier and plenty of space to store 20 years worth of Association papers! I must mention that keeping our

membership programs up to date has been crucial. We have a very good volunteer who keeps lists, takes renewals, sends out renewals and so on. Wendy also does our website.

**(5) Funding is a vitally important part of an organization. Where do you get the funding to run the Association? Do you have any 'large' donors? Is the WCFSA expensive to run?**

Our Assn funds come from our membership. All Wisconsin people can join free of charge as it is our belief that getting information to people is priority one. How we support our infrastructure is donations, none too small. Most often, people add \$5 or \$10 or more to their membership, so it begins to add up. They know we rub a nickel to get a dime and that we are volunteers. They also know that those donations help people get information when they can least afford it.

We have no large donors. CFS is not a popular community cause. What we do have is a big hearted board member and her spouse who own the office space. They "donate" that plus utilities.

Is it expensive to run our ORG? We filed a 990 only twice in 20 years. That means that contributions (not memberships) exceeded \$5,000 only twice. One year we were about \$200 over the limit and had to fill out that Mega 990 tax form. After our fundraiser for the PANDA project, we were able to set aside a good amount of funds ONLY for PANDA project development (see below). We do not use this to support our day to day expenses.

**(6) Can you give us a history of the group over time? Have you taken on new initiatives? Have you changed focus? Are you doing different things from when you started?**

WI started out as most education and awareness groups - providing information and assistance to patients and their families. We had 27 operating support groups in the state. Four times a year I sent packages of medical articles, envelopes, letterhead and other supplies to group leaders plus I would call people a few times a year to see how they were doing.

From 1987 until 2000, we acted as a support group, but the landscape changed. We were not able to offer patients much help. Once most of us had Internet capabilities and could look at the larger picture, our board changed the focus. We realized that our 6 years of intense focus on UW - MADISON Hospitals and clinics had not yielded any long standing positive results. At a meeting in 2001 with the UW people who set up a CFS "program" we were told to go somewhere else. I clearly remember the hospital administrator telling me that the reason we got our CFS "program" in the mid 1990's was because they thought that our organization was going to sue the hospital. So, 6 years later, I saw that if we were going to help one person it would be by going right around the powers that be in the medical community. That administrator was honest with me and had that been the case 5 years prior, we would not have wasted out precious energy with this institution.

In 2001, our board conceived the PANDA (Patient Alliance for Neurological Disorders Assistance) project, that is, to create a diagnostic clinic for anyone with disorders similar to CFS. We found out that MANY people with unexplained chronic symptoms have little help and support from the medical community. The structure of the healthcare system disallows time for patients with chronic illnesses that are time consuming. Add the unknowns of CFS in the mix and most MD's find dealing with CFS daunting. One MD told me that his colleagues would rather "run the other way than see a patient with CFS."

SO, we are working on PANDA piece by piece. Who ever heard of a support group opening a clinic?

**(7) Can you tell us more about PANDA? How is the project progressing?**

In 2002, after a number of board meetings, we wrote the first draft of "THE BIG IDEA." What would a clinic look like if we could have anything we wanted for people with CFS? Draft number 3 is on the PANDA website at [www.panda-clinic.com](http://www.panda-clinic.com). Our first step was to go to all the groups who have similar illnesses. We wanted to know patients' medical needs. This was enlightening because vital groups such as the local MS group were polite, but really wanted nothing to do with a CFS group. In all communications, we made it clear that our organization was not looking for funding of any kind. Despite listing unmet medical needs, a mile high barrier disallowed further communication with all patient groups. I was shunned at a post polio conference. This is no exaggeration. I am open and knowledgeable about CFS, but people were not at all accepting that I could place CFS on par with Post polio. Enlightening.

The next thing we did was to survey any organization in Madison that served disabled populations. We called and sent short questionnaires. The results were dismal and if the calls I made were any indication, mention of CFS begged the listener to even take me seriously. Enlightening.

The 2004 AACFS conference bid was open, so we decided that if that medical conference were to take place in Madison, we might open pathways with not only medical people, but with other patient groups. So, for over a year we worked on hosting the international conference. We had one MD attend from a small town up north and several alternative medicine people, but no one attended from Madison or Milwaukee. Enlightening.

Because "THE BIG IDEA" is a good idea, we are still chipping away at how to manage the project. In September of 2005, we completed a huge fundraiser that put a considerable amount of money into a CD for the PANDA project development.

This year, we are targeting medical education, and networking in other ways to rebuild our clientele. In other words, if the problem is a prism, we keep turning it to see if we can see another way through to the other side.

Currently, a team of graduate school Occupational Therapy students is writing a grant for case intervention services. There is a huge need to develop service brokers who support regular medical doctors in their work with CFS patients. PANDA is about medical care AND quality of life. Maybe if we can work on giving something, we will have better cooperation from the medical people who find it too hard to work with CFS patients.

**(8) Support groups often provide valuable conduits to CFS physicians in their area. What is the state of CFS physician support in Wisconsin? Are many physicians that are knowledgeable about and competent in dealing with CFS? Have their numbers increased over time?**

The numbers of MD's willing to see CFS patients has decreased over time. We had a list in 1992. Now, I have one very good MD to refer people to in Madison and none in Milwaukee. I think MD's lack information and even if they have the interest, they do not have the time to sort out all the CFS issues. Think of it. Reading inches of patient history and taking a good history is basic, but that more than covers the 15 minute time slot most MD's are allotted per pt visit. So patients get some treatment of symptoms, but they need to mind their own store.

It is a difficult question. Primary care is a huge problem. Many women do not get regular mammograms and pap smears because each time they have an appt it is for some acute

problem. Through PANDA, a huge idea, we have made progress with other types of medical professionals and will continue to work with one MD at a time instead of institutions.

**(9) Your website states the WCFS "*encourages communications among agencies, institutions and concerned individuals*". What does this entail? Do you interact with the local and state government officials?**

In 2001, we began to explore this part of our mission statement. Prior to that, going through the Public Health Department and other agencies was hit or miss. At first, I was appalled by the need to NOT know about CFS. Now I understand that the problem is economics, not ethics. We are approaching agencies in a different way. In addition, my national work has had impact locally. I had no idea that would happen.

**(10) You've worked on national CFS issues recently. How did that come about?**

Because of our years of work and the continual need to reexamine the problems, I keep asking the question why. I am one of the most curious people ever which is tough with CFS. So why is it so hard to get help? Why do MD's toss up a barrier? Why do some advocates send one another hate mail? Why are patients accused of making this mess? Who is in charge? It is endless.

Thus, to get answers, I began to look at the big picture which ended up looking like the Grand Canyon of CFS issues - NIH funding. Now there is an interesting start to looking at bigger issues. It was like nuclear physics for me. I can hardly make change at a restaurant, but I pushed to conceptualize the funding process at the NIH. That was in 2004.

When Casey died on July 4<sup>th</sup> of 2005, that same afternoon I sent out many e-mails that said, "Casey died this morning," I did not care about anyone's sensitivities. I just could not bear to shoulder this alone. So, to whom did I send the e-mails? People with CFS. Why? I don't know...maybe because I knew that they understood loss and would help me get through it? They did. People from all over the world e mailed me and I received letters from so many people I had never met. Perhaps the loss cannot be greater and to some it was symbolic of how this illness is so misunderstood. During that time, I made it clear that I will continue to work for patients, for my son and for myself.

In my little town of Sun Prairie, in Madison and in Wisconsin, I am just a person next door. Perhaps, my growth as a human being, my self-confidence and assurance that what I do is right for me and will make a difference is all I need to keep going.

**(11) You represent the entire state of Wisconsin. Your website states that you act as a clearinghouse for CFS information within the state. How does this work? What is your relationship with the local CFS support groups? Do you interact with them much? How about with other CFS state organizations.**

I don't see myself as representing the state of Wisconsin if we cannot find 80% of CFS patients! What I do is a drop of rain in the Grand Canyon of CFS needs. I interact with many people at all levels. ANYONE who comes to us can get help with medical information, disability, coping and finding an MD. 30% of our membership is out of state, so these people just get our quarterly publication *Lifeline*. I am more of an advocate than I used to be and that is time consuming.

We had 27 groups in Wisconsin. All but 2 are gone. I think this happened for several reasons. As leaders burned out, it was hard to find replacements. We had 3 group leaders/ contacts die, two of cancer and one of liver failure. Information access has changed. Some people got better

or were rediagnosed with another illness. Lastly, some people lose hope and just accept the way things are. They do not go to the doctor and do not keep up with CFS news.

I am working on communication & some projects with state groups and most importantly with the small regional people who are the backbone of any CFS networking. I think these people go unrecognized for their time and energy zapping efforts to help people day to day. We have the best reason in the world to work with all groups. That reason is to establish a CFS community.

Also, in 20 years, especially after internet communications, I have seen so much reinvention of the wheel. Small groups and individuals have similar ideas and do a huge amount of work that duplicates the work of a person in another state. What I have learned is that we must keep working along, be open minded and inclusionary. Expectations on people have to be tossed out the window. Some patients are so harsh with others who are vulnerable that we lose people with good skills.

Vocal advocates are the people we need to create pathways, but I have found many of these to be the least kind with patients and with each other. If we agreed on things, there would be no need to change. Also, in my opinion, if anyone is in this work for personal glory and to scoop up power to feel like a worthy person, that advocate will burn out and always feel loss.

**(12) What about with the big national group - the CFIDS Association of America (CAA). Is the Wisconsin CFIDS Association in communication with the CAA? Are there ways the local groups can support the CAA or vice versa?**

This is a touchy issue. I think that the CFIDS association started out to be everything to everybody. After all, CFS presents huge issues in all arenas. However, if you look at the CFIDS ASSN 990 tax form and compare that to the National MS society or some other illness group, they do not have the money to work in all areas.

In 1988, Wisconsin and other state groups started a National Federation. A constitution and by laws was set up and 14 states had signed on before Ruby and Genie pulled Wisconsin out over misunderstanding about election of board members and officers. I have a copy of the federation papers at the office.

I mention this because we had a golden opportunity to form state chapters that would share equally in the infrastructure of a parent organization. The CFIDS Association of America has not developed state chapters. I think this is a mistake. What has come of it is a loyalty clash...either advocates and state groups are with the CAA or against them. That is a non productive thought process. Yet, the reality is that many state groups and individuals who have been working as long as Wisconsin, choose to either go around the CAA or pay tribute to that national group out of some fear of reprisal from someone else.

I support the CAA lobby days because the group has made huge gains in congress. One has to go there to see that congressional delegates *KNOW* about CFS. The CAA has been criticized for this effort, too and that is unfair. I support the recent PR campaign, but would add that at the end of the day, the 200 + local groups and individuals have to take the calls and clean up the mess with few resources. As I said, it is a touchy question.

**(13) The WCFSA is one of the older CFS support groups. What is your membership now? Has it picked up or declined or stayed even over the past 10 years? How many people are really active in the support group? Do you feel you are expanding, slowing down or kind of just maintaining where you're at?**

As of August 24, 2007, we will be legally incorporated as a non profit for 20 years. I think that makes us the oldest operating state group or regional group in the country and older than the CAA. Membership is about 395 including MD's and advocates that who receive a free *lifeline*. We voted early on to get these people information no matter what. Members have changed, but the level has not started to increase until this year.

As I mentioned, we have no active support groups now. We no longer see our organization as a support group. We have BIG ideas and this seems to be working better.

We will start support meetings with a different view on April 21 in Madison, followed by Milwaukee in May. One more educational meeting will be held in each city in the summer and then our fall seminar is in October. We now have more to offer and view people as clients because of the PANDA project.

If you are asking how many people do the work, then that would be about 30 including board members. Everyone is sick except my husband Bruce, so it is hard to sustain activity, but we manage. From an Executive Director's point of view, our board has skilled and creative individuals, most of who are not interested in CFS politics. They just want to help patients as best they can.

**(14) When you look back at what you wanted to achieve with this group and what you have achieved how well do they match up? Do you feel the WCFSA is making a difference with this disease?**

What we have achieved...how can one know what will be accomplished in uncharted territory? In the beginning, I just wanted to get people some help. I spent hours and hours on the phone. I did the kids support group and the support network organization. Over the years, I spend less time on the phone, more time writing letters and proposals for projects and of course, mega time looking into CFS research funding.

Expectation is a nasty word in this working environment. What I would like and what I can expect never match up. I can accept this and it only becomes frustrating when people rag on others who are sick. People with CFS may be hostile and cynical at times, but with good reason. My pet peeve is when patients are blamed for lack of progress. Is that stupid or what? We did not cause these illness problems and did not muck up the case definitions or fuel the bias. It *feels* sexist to me. "*Just go away little girl and remember to be good.*"

Yes, we are making a difference, but so are the Vermont, the Northern VA group, the Atlanta group, and the Reaching Out .Org people. It is very cool what these people, among others can accomplish.

**(15) Pat you've communicated to me your worry about all the lost CFS patients; those in terrible financial straits and bad health many of whom probably don't even know they have CFS and have been relegated to the fringes of society. These people are living a very marginal existence, they're not in touch - they're either surviving or not. There really no outreach to these people is there?**

Many of us without our networks and some money would be on the fringes of society. My thought is that we cannot keep talking about the economic impact and the 80% undiagnosed as if to use the statistics to get attention. Who cares unless we have a way to find these people?

I will propose at the CFSAC meeting a national outreach program. This is a collaborative project with some other groups and I am really enthused about it. If the pilot works, however,

we could be in for a flood of sick people calling to get information. This might flood local sliding scale and free clinics with people who have had long standing illness, but are on the streets. Think of it. Where are those 640,000 people?

**(16) Have there been issues you've wanted to take on but haven't been able to? If so what has stopped you from doing so?**

Issues. I have to shut out half the issues I would like to explore because I do not have the energy. Then again, I have this brain that likes first hand information, so I spend more time digging for information than is good for me. I have realized over the years that everything mutates, variables change and with it, I must keep a fresh idea about the reality of NOW in the CFS world.

**(17) What do you think the future hold for the Wisconsin CFS Association? Is the support group is on firm ground? If you look ahead 5 or 10 years do you see any particular pitfalls or opportunities emerging?**

The WCFSA is on firm ground. We may be slow, but we produce good work. I hope in 5 years to have part of the PANDA project complete so we have medical help in Wisconsin. Pitfalls? I think we have made it through about all the pitfalls I care think about. I will think about the hills☺ ))

### Advocacy and Personal Issues

**(18) Several years ago you had a terrible tragedy when your son Casey, who also had CFS, died suddenly of an undiagnosed cardiac infection - something that presumably could have been treated if it had been found in time. The medical examiner was reportedly 'shocked' at what he found. This must have really brought home in a very personal way how terribly under funded CFS research is and how little appreciated the disease is in the medical community.**

First of all Casey died in an instant, so nothing would have helped him the morning of July 4<sup>th</sup>, 2005. What really made me crazy was the scar tissue from past viral infections. He would have been more inclined to go to the MD and not ignore symptoms...and he was bullheaded...if he had not been treated so poorly when he was a little boy. Kids remember what outside authority figures do and say. Oftentimes, parents cannot override messages that are internalized in a kid, especially when the child is getting close to middle school age. Hey kid...you are not feeling what you think you feel! It causes such self doubt. Aside from that, a little boy is supposed to be rough and tough and coordinated. Being a bully is better than a wuss. It's a school thing, still promoted and it places such extreme expectations on little boys to take it like a man. ICK.

By the time Casey died at age 23, he was just beginning to pay attention to himself again and he was doing well. I found out later that anyone with heart problems should not be lifting. Casey could bench 245 pounds and we had a gym in the basement. He took pride in that activity which he started in high school.....= big and strong!. But...there is no turning back.

The coroner and the medical examiner ignored me. What can be done? Nothing. Something could have been done when Casey was a child, so ill, every single day. I became Casey's worst enemy in the MD office. I have one Pediatric diagnostic report saying that Casey was "*mimicking his mothers CFS behavior.*"

A hard reality is that I could not have saved him no matter what I did. Maybe now with the 2007 Pediatric Clinical Definition of CFS, Kids will be taken more seriously.



I did start my NIH work in March of 2004 prior to Casey's death. After July 4, 2005, I was ready to toss the folders off my computer. But, I pulled them out of the trash because I wanted to finish what I had started.

**(19) Casey's death became really well known - it was one of the first CFS deaths that I heard of. You set up the Casey Fero Memorial Fund to build a CFS tissue and blood bank. Can you tell us a little about this project - why you chose this one in particular, what it will do, where it is located and how people can contribute to it?**

The coroner and everyone else will deny that it was a CFS death. With the medical history and Casey's last days, I know it was related. Again, right now at this place in time, nothing can be done about that.

I chose this project at the suggestion of Jean Harrison, President of MAME, another small group. She reminded me that in the GAO 2000 report on CDC and NIH funding, it was concluded that a brain tissue repository be set up by CDC. That had not been done. I e mailed various places, but all had private freezers and such. No one was interested in a bio bank. I think that is odd. How can we see what is really going on inside the cells unless they can be examined?

Drs. Knox and Carrigan (Wisconsin Viral Research) agreed to house a repository, so we started to raise money for a freezer. Once I had \$10,000, I asked WVR for a purchase order, but they had decided that creating a public access blood and tissue bank was a huge, huge venture. So I e mailed Kristin Loomis (HHV6 Foundation) and that request eventually came to Annette Whittemore who, unbeknownst to me was, with Dan Peterson, setting up the Whittemore-Peterson Institute for Neuroimmune disorders on the University of Nevada campus in Reno. They said YES, we will house the bio bank.

What is not known is that Casey's tissues arrived unusable to WVR, and of the 7 blocks of tissue in paraffin at University of Wisconsin, 6 are missing. This also makes me crazy. Again, we do what we can, but sometimes, the outcomes are sad.

People can contribute...oh yes they can, because repository equipment costs are huge and once up and running, maintenance is high. Donations can come to the CASEY FERRO MEMORIAL FUND at our association address. Contributions can be made in honor of a specific person or in tribute to someone who has passed away. A second fund for Casey and for Beth van den Berg, a deceased Wisconsin member has reached about \$900

**(20) Pat, you were given the CFS Female Advocate of the Year Award at the P.A.N.D.O.R.A./IACFS Patients Conference in Fort Lauderdale, Florida in Jan, 2007. What do you think is the biggest challenge facing CFS advocates at this time?**

I believe that we have no CFS community and those who are able, must try to reach those not diagnosed or misdiagnosed. We are few. They are many.

**(21) Pat, you've met with Dr. Pinn and Hanna - the top two CFS officials at the NIH, and Dr. Reeves, the leader of the CDC CFS research program. They are important figures; their budgets in relations to the agencies they work at are really small but they still dwarf what private advocacy groups can raise. Leaving aside for the moment whether or not they are taking the right approach, what is your sense of these people - are they government bureaucrats that somehow got hooked into studying this crazy disease and really not happy about it or are they really committed to figuring it out? Where on that continuum do you think they lie?**

Another touchy question. I think to survive at all in a government bureaucracy, one has to learn when to step forward and when to step back. It's a game. People can criticize all they want, but I think if Drs. Pinn and Hanna want a job in the morning, they have to juggle all the politics. DO I think both are "really committed" to figuring it out? No. That is an unreasonable expectation. Doing the job well is reasonable and I have no idea what constraints and assets these people have to work with.

Dr. Reeves is another issue. I think he is totally committed to the scientific puzzle and if he had an unlimited budget, he would pursue CFS with obsession. I may not agree with his approach, but I believe he is committed.

**(22) Pat, you've been exploring the alarming decline in CFS research efforts at the NIH since the Cooperative Research Centers closed and Office of Research into Women's Health took over with came up with new and more rigorous criteria for funding CFS research. This has been a difficult transition period to say the least. The NIH has funded some great stuff - some really innovative studies - but research levels overall have gone down and they've thrown a lot of non-CFS research stuff into the CFS research basket. That issue has gotten attention from you, the CFIDS Association of America and others. Do you think your complaints have gotten through to people who could do something about them?**

I understand that the Center for Scientific Review (CSR) is undergoing a complete overhaul on grant making. Toni Scarpa, the Director, did not look at these needs because of CFS. On the CSR website, within a few months of Dr. Scarpa taking office in July of 2005, he began to have listening sessions. Problems with the review process flooded the site. I believe CSR Powers that be are trying to do the right thing. But reality says...who has the biggest machine to oil? It is not CFS. I am fearful that CFS research, a beautiful stand alone, will be lost to larger areas...inflammation, pain and fatigue.

I HATE THE WORD FATIGUE and its commonplace use. I cannot watch a sports program without listening to announcers mention so and so is "fatigued" Car parts get fatigued and break. Well, fatigue has nothing to do with me or anyone I know with this illness.

**(23) Pat you've attended and spoken at meetings of the CFSAC, the federal advisory committee for CFS (click here). CFS patient attendance at these meetings has been alarmingly low - not a good situation for a disease that desperately needs more governmental support. You've been attending these meetings for years. Is attendance lower than in the past? If so why do you think this is so?**

Actually, I attended two CFSCC meetings and two CFSAC meetings. Attendance was high at both CFSCC meetings, but not much was accomplished. Low attendance at CFSAC meetings is due to the fact that we have 15 days or less to figure out the finances and logistics of the trip. ALSO, I am hoping that if CFSAC meetings can be web cast, people will watch and become interested.

Look, day to day is hard on people. Add the politics and meetings and pages to read, many people just cannot do it. Plus, it is expensive and most patients do not have the funds to go the DC for a few days. THIS is why we need web casting. It's an accommodation for an illness that is suitable for the patient population. If they can web cast a council meeting on sleep disorders because they recognize that the patient population might not do so well in DC, they can web cast a CFSAC meeting.

**(24) The WCFSA sponsored the 7<sup>th</sup> Annual AACFS Conference in 2004 and you were at the 8<sup>th</sup> Conference as well. Looking at the two do you think we've made much progress in the last two years?**

VAST progress has been made in two years. When we include the international community, we leap ahead. The problem is in practical application in our communities. I see little progress in this area and little progress in advocacy. PANDORA is a start...working in collaboration and providing special events for advocates. This is good.

Yet, I keep thinking about the plight and the power of those 640,000 missing people with CFS....we need them and they need us.(04/16/07)

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The Wisconsin CFS Association: (<http://www.wicfs-me.org/>)

Panda: <http://www.panda-clinic.com/index.htm>